

Information specialists: indispensable partners in modern research projects

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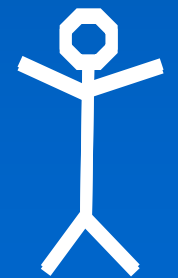
Medical Librarians Matter For Evidence Based Medicine

9 September 2016

Contents

- The challenging question: What works?
- Where is the answer and how to find it?
- Accumulating knowledge, systematic reviews and information specialists
- Where information specialists can play a crucial role to improve the medical science / care - process

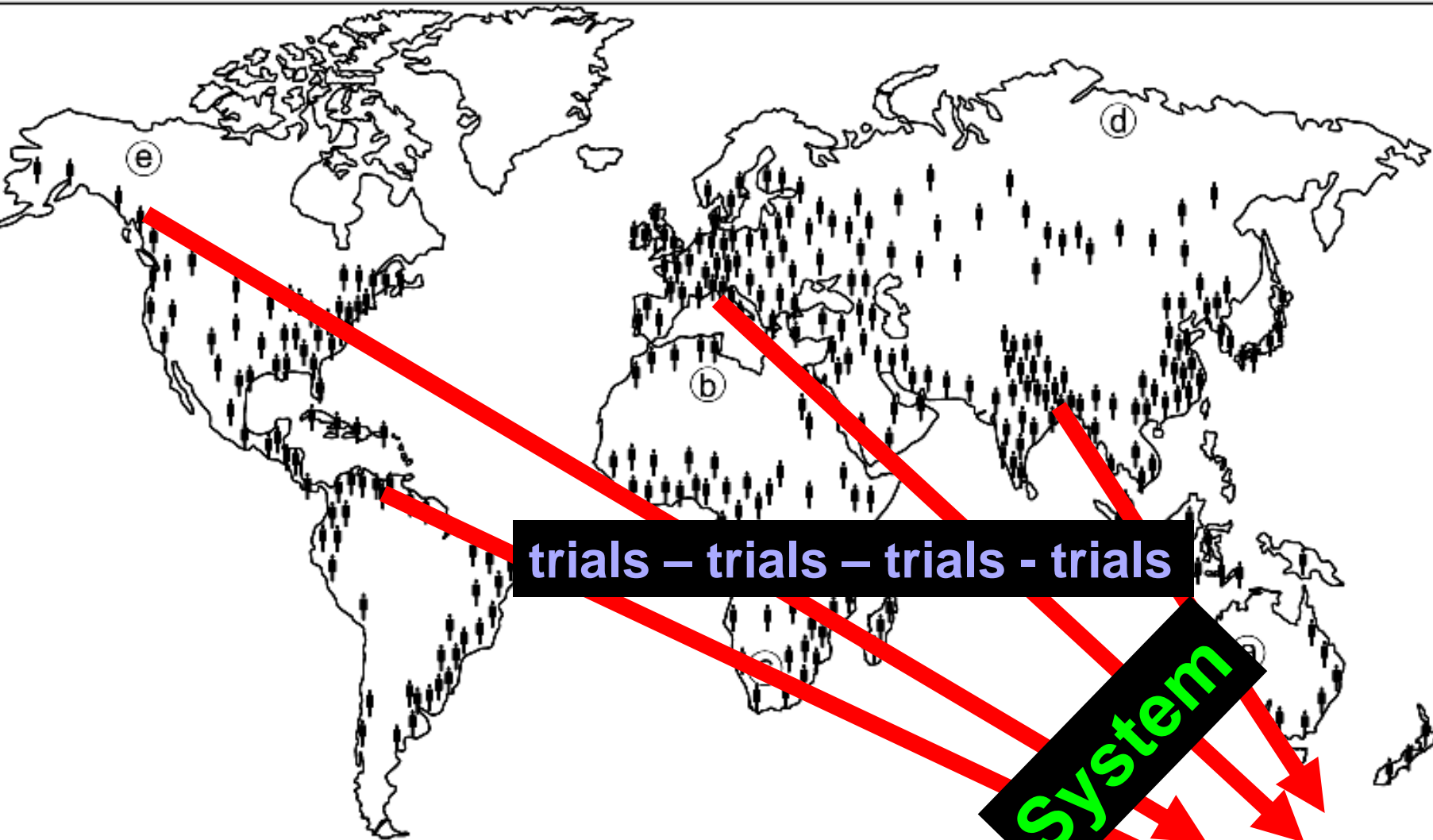
**What is the optimal decision
for the selection of the right
diagnostic procedure or the
best therapy?**



Neumann



Neumann



trials – trials – trials - trials

System

Information from similar persons with same treatment

Neumann



THE CAMPBELL COLLABORATION

What helps? What harms? Based on what evidence?

- The Campbell Library
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- What is a Systematic Review?
- What Works Global Summit
- Future WWGS
- Previous Colloquia
- Request for Submissions

What Works Global Summit

Putting evidence to work for better policies, programmes and practice

**The What Works Global Summit 2016
London, 26-28 September 2016**

Pre-conference workshops: 24-25 September

We are now accepting submissions!

Submission deadline: 25 April 2016. Read more [here](#).

The Campbell Collaboration, the [Centre for Evidence and Social Innovation](#) (Queen's University Belfast), the [International Initiative for Impact Evaluation \(3ie\)](#) and [Sense about Science](#) - announce the first What Works Global Summit this autumn 2016 in London, UK. The event addresses evidence-informed policy globally across all sectors, with active participation from both producers and users of evidence.

To join the conference mailing list, please email wwgs@campbellcollaboration.org with the subject 'Mailing List'. Information and updates will be posted on Twitter via [@C2update](#) and #WWGS2016.

Home > What Works Global Summit



What Works Summit



**What Works Global Summit 2016
26-28 September, London**

Putting evidence to work for better policies, programmes and practice.

Pre-conference workshops:
24-25 September

Home > Coordinating Group

Coordinating Groups

The Campbell Collaboration's Coordinating Groups are responsible for the production, scientific merit, and usefulness of Campbell systematic reviews.

There are at present six Coordinating Groups:

- [Crime and Justice](#)
- [Education](#)
- [International Development](#)
- [Methods](#)
- [Social Welfare](#)
- [Knowledge Translation and Implementation \(former Users Group\)](#)

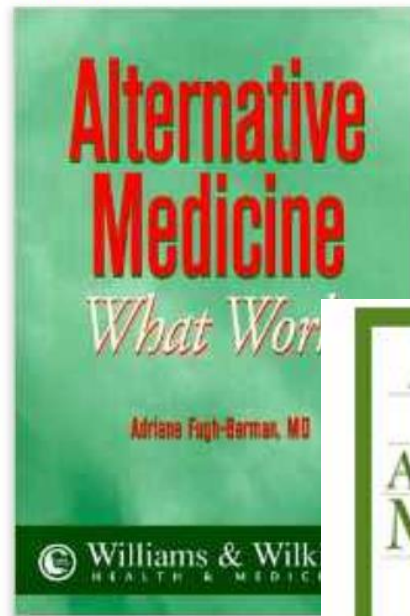
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- What Works Global Summit

Alternative Medicine:

Con 1st Edition

by Adriane Fugh-Berman (Author)

★★★★★ 5 customer reviews



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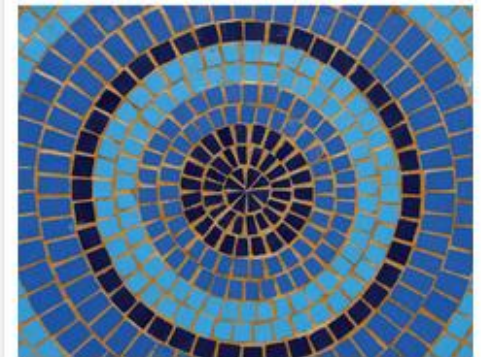
A DOCTOR'S GUIDE TO ALTERNATIVE MEDICINE



MEL BORINS, MD
Foreword by Bernie Siegel, MD

FINDING WHAT WORKS IN HEALTH CARE

STANDARDS FOR SYSTEMATIC REVIEWS



Status: Final Book

Downloads: 10,983



Learning What Works

< Prev

Next >

Infrastructure Required for Comparative Effectiveness Research

Workshop Summary

Institute of Medicine (US) Roundtable on Value & Science-Driven Health Care.

Washington (DC): [National Academies Press \(US\)](#); 2011.

ISBN-13: 978-0-309-12068-5 ISBN-10: 0-309-12068-3

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[Hardcopy Version at National Academies Press](#)

Search this book

Excerpt

To improve the effectiveness and value of the care delivered, the nation needs to build its capacity for ongoing study and monitoring of the relative effectiveness of clinical interventions and care processes through expanded trials and studies, systematic reviews, innovative research strategies, and clinical registries, as well as improving its ability to apply what is learned from such study through the translation and provision of information and decision support.

Transfer of Research into Practice

Evidence
production

Answers to medical questions

- Clinical (randomised / controlled) studies
- Epidemiological (observational -) studies

....

Body of Evidence



**1968 McMaster Univ.
Hamilton, Canada**
1971 Archie Cochrane, UK
1996 Germany
1998 Cochrane Germany

Evidence
application

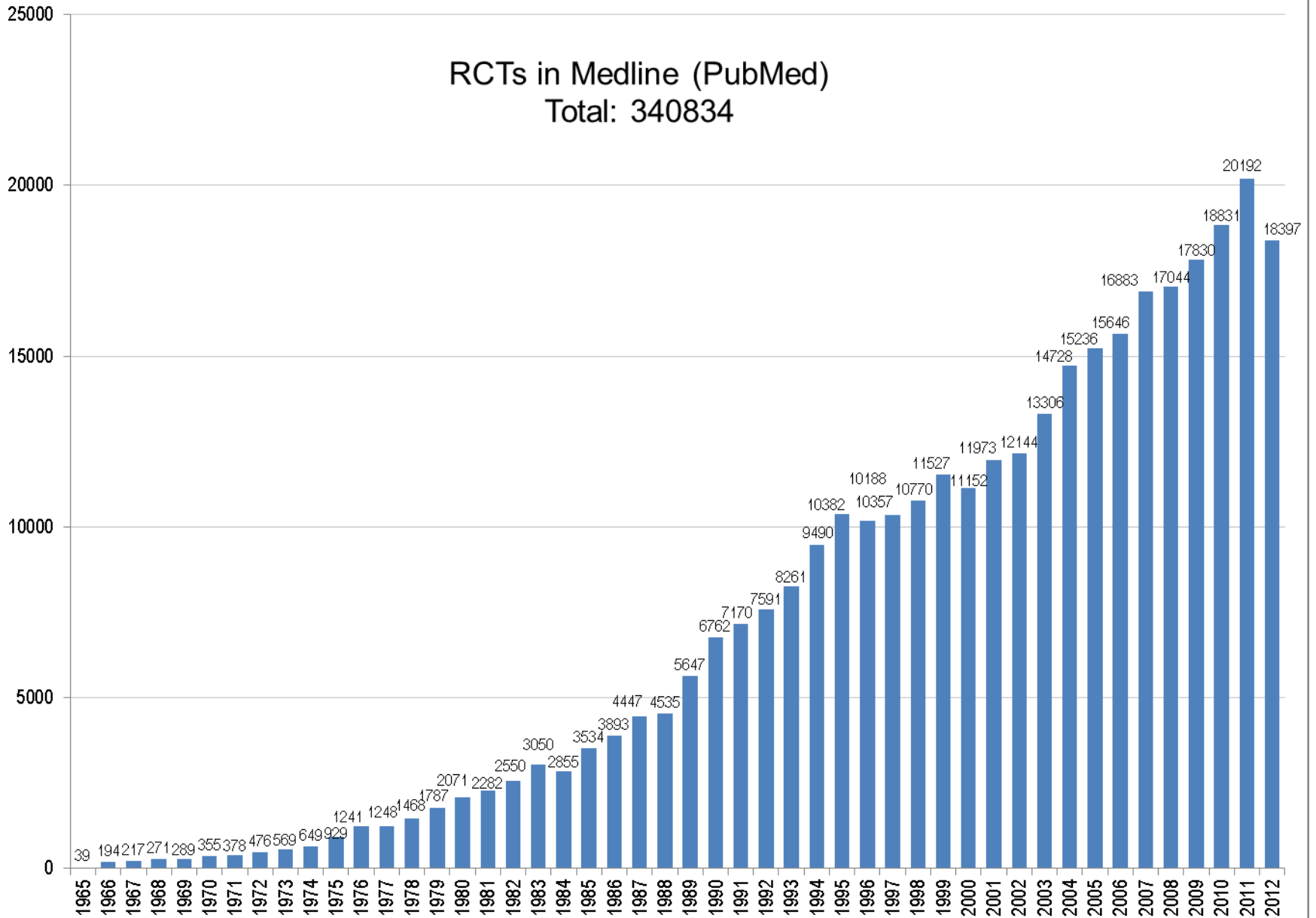
Knowledge Translation

- Practicing physicians
- Health authorities, sickness funds, insurances, institutions
- Clinical research
- Patients

The trial deluge

RCTs in Medline (PubMed)

Total: 340834



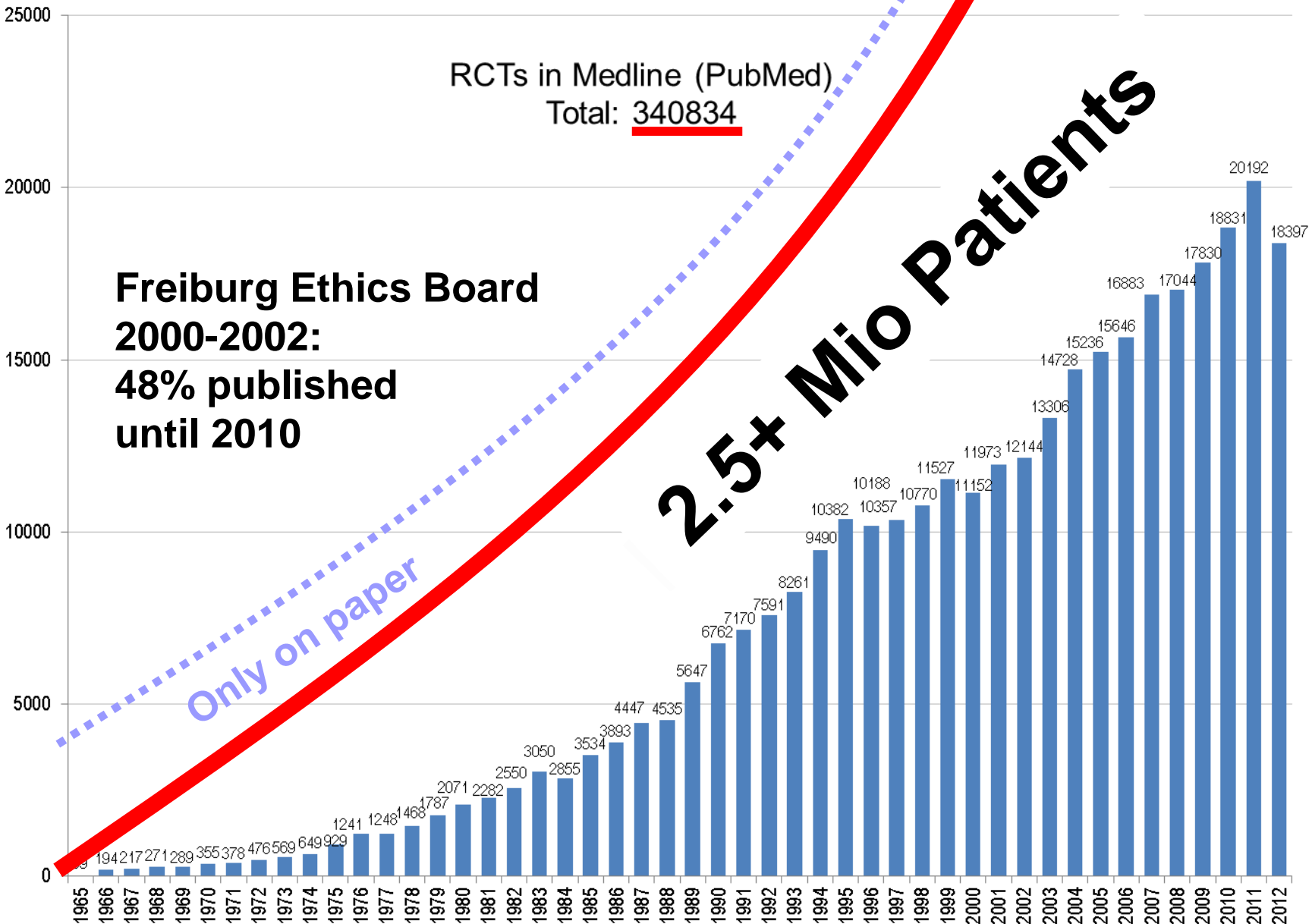
The truth

RCTs in Medline (PubMed)
Total: 340834

Freiburg Ethics Board
2000-2002:
48% published
until 2010

2.5+ Mio Patients

Only on paper



Transfer of Research into Practice

Clinical studies (experimental, randomised, controlled, prospective)

Epidemiological studies (observational, retrospective)

Systematic Reviews 

global



EBM

Health Technology Assessment (HTA) 

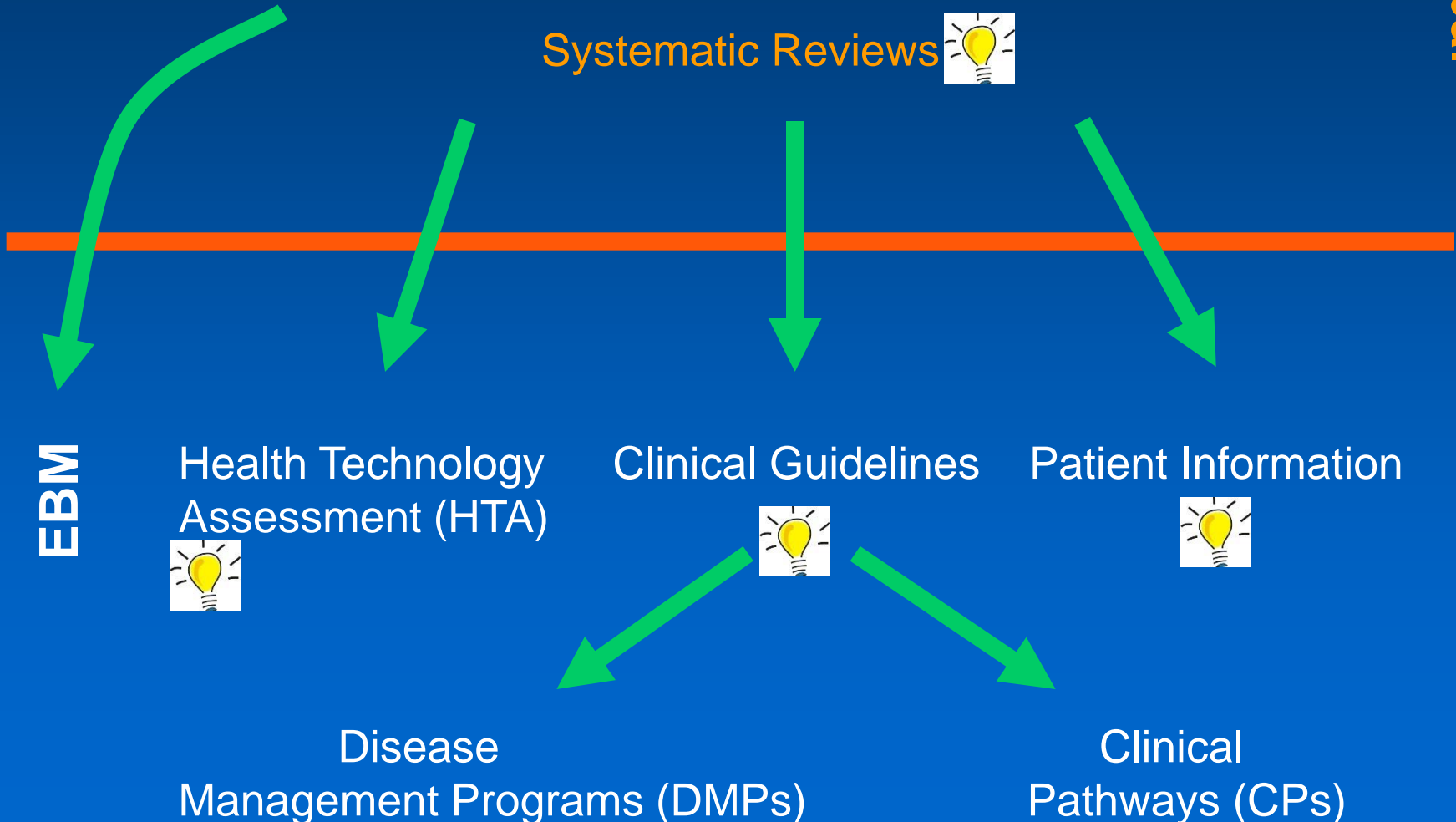
Clinical Guidelines 

Patient Information 

local

Disease Management Programs (DMPs)

Clinical Pathways (CPs)



Leaving things out

Selective reporting =

1. Hiding whole trials (classical publication bias)
2. Hiding (or distorting) information from trials which are published
3. Spin: Interpretations which have nothing to do with the trial results

Really harmful?

Is selective reporting harmful?

Yes, because it leads to a wrong information base for

- Systematic reviews
- User specific summaries like HTA reports, clinical guidelines, patient information etc.
- All further decisions and action based on it

Due to this misinformation patients suffer or die unnecessarily.

Example 3



One million children were included in a deworming trial from India with mortality as the primary outcome. This was completed in 2005 but has not been published in 2012.

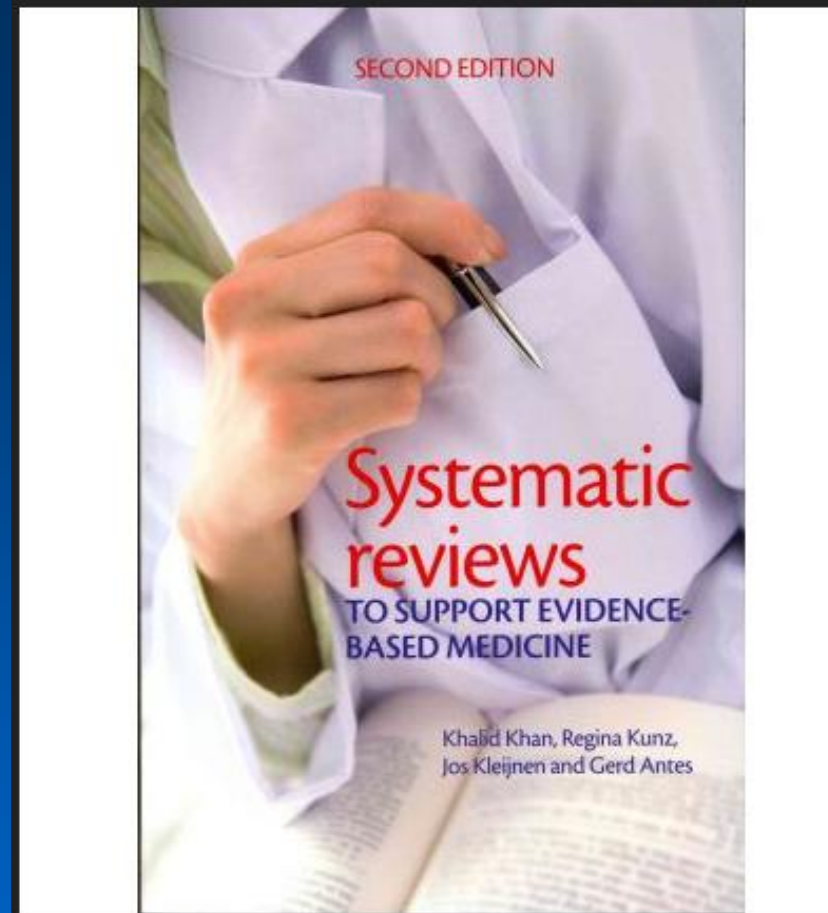
DISCUSSION

(SECTION ON BIAS)

Publication bias: We are uncertain about the number of unpublished trials in this area. We know of two unpublished trials: 1. [Hall 2006 \(Cluster\)](#) is unpublished. This large trial from Vietnam, with 2 years follow-up, kindly provided by one of the authors, did not demonstrate a significant difference in weight gain. Clustering was not taken into account in the analysis, which artificially narrows the confidence intervals. In this update we included the results of this trial in meta-analysis by imputing an intra-cluster correlation coefficient, calculated from the adjusted data from [Alderman 2006 \(Cluster\)](#). 2. **The DEVTA trial** (deworming and vitamin A; <http://www.ctsu.ox.ac.uk/projects/devta>), the world's largest ever RCT, which includes over a million children randomised in a cluster design with mortality as the primary outcome, remains unpublished 6 years after completion. We have corresponded with the senior author, on several occasions. We also wrote a letter to the Lancet, asking for publication of this important study. When this letter was accepted, the authors submitted the manuscript to the Lancet within a week, and we withdrew our letter. However, at the time of writing (April 2012) the paper is still not published, for unknown reasons.

The knowledge refinery

1. Framing the question 
2. Systematic search for evidence from relevant trials and studies 
3. Critical appraisal of trials - inclusion
4. Summary and quantitative synthesis (if possible)
5. Interpreting and putting in context



July 2011

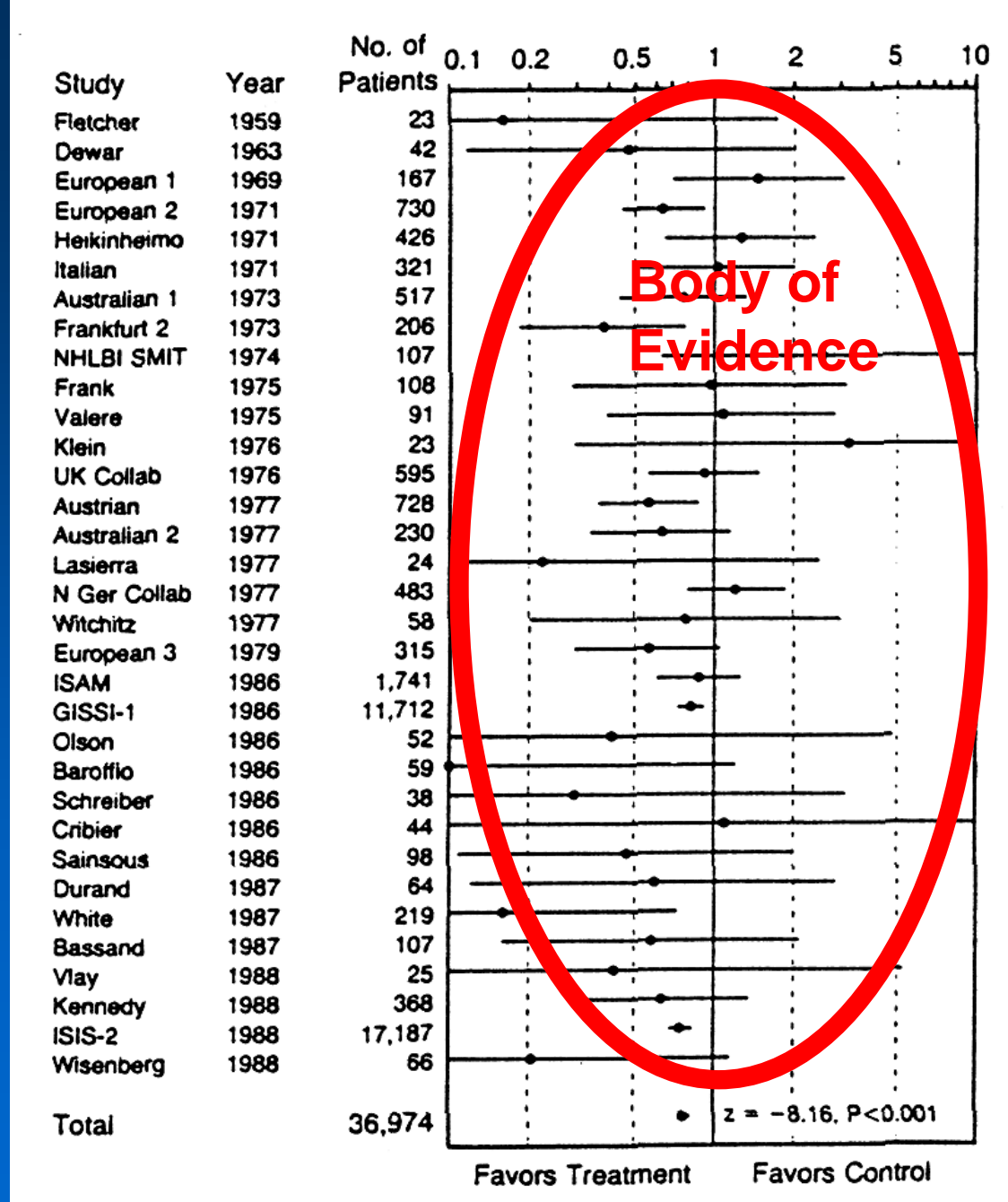
Updating!!

Produce unbiased view of “all” evidence

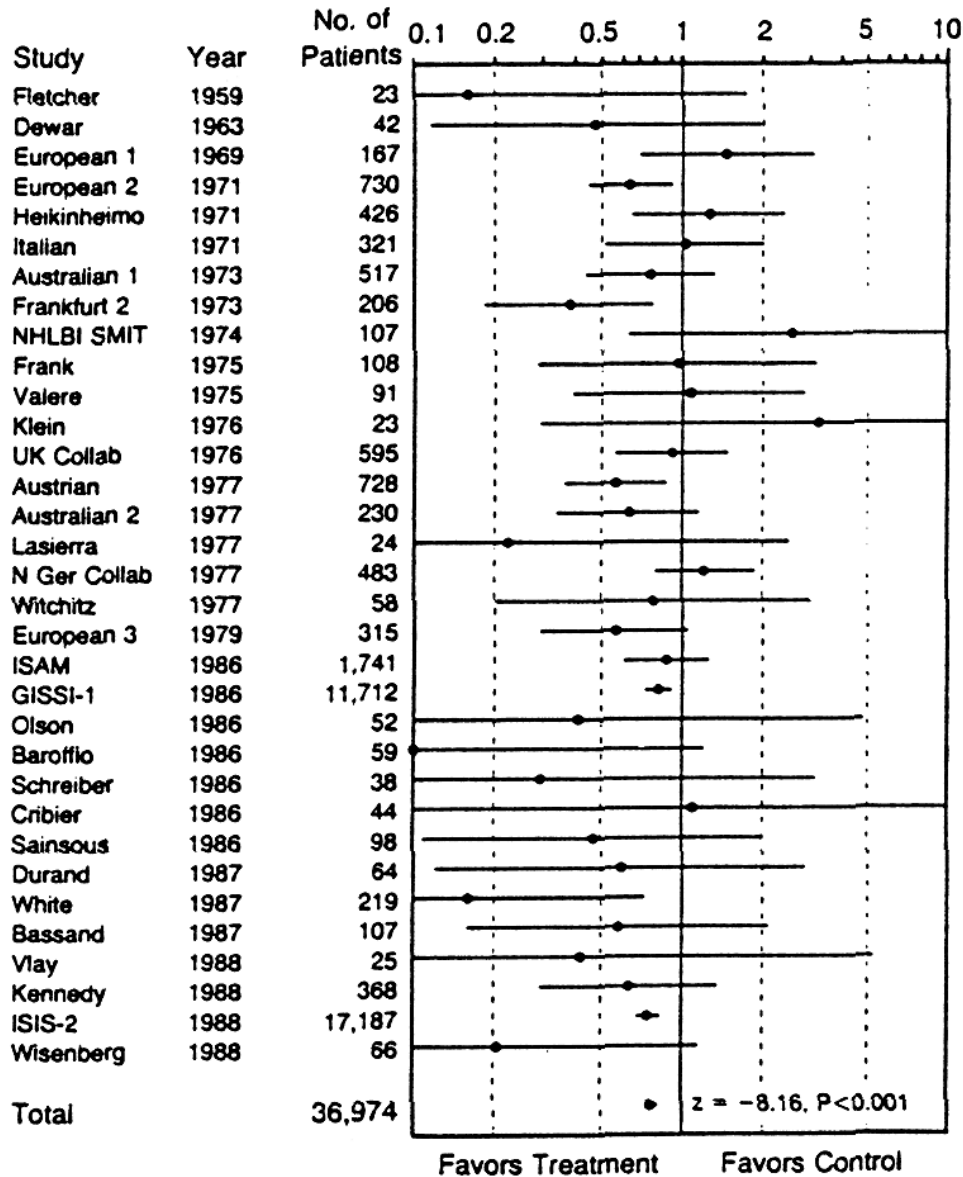
Example Thrombolysis after acute myocardial infarction

NEJM 1992

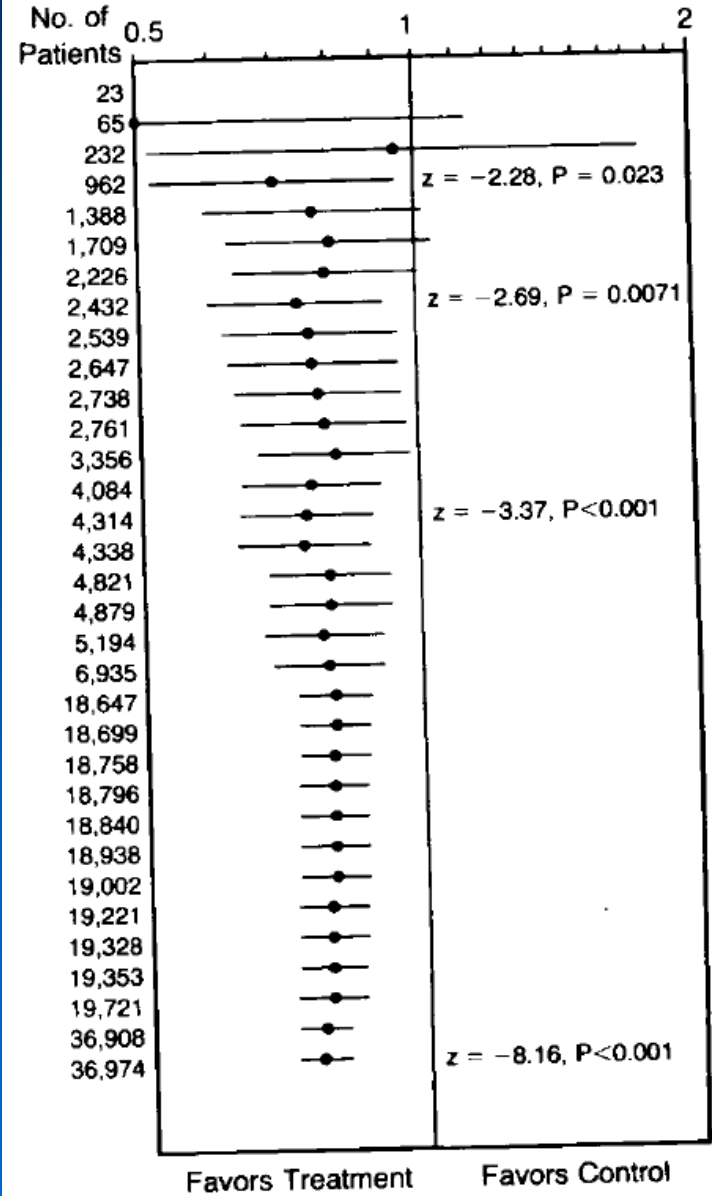
Forest Plot



Forest Plot:



Cumulative Forest Plot:



Open questions

- No accepted stopping rule
- Have all relevant trials been identified and considered?

**Need „all“ (!) relevant trials:
2016 no reliable method and procedure**



Ultimate aim

All relevant data

from

all participants

in

“all” relevant trials



„All“ trials ?



Quality?



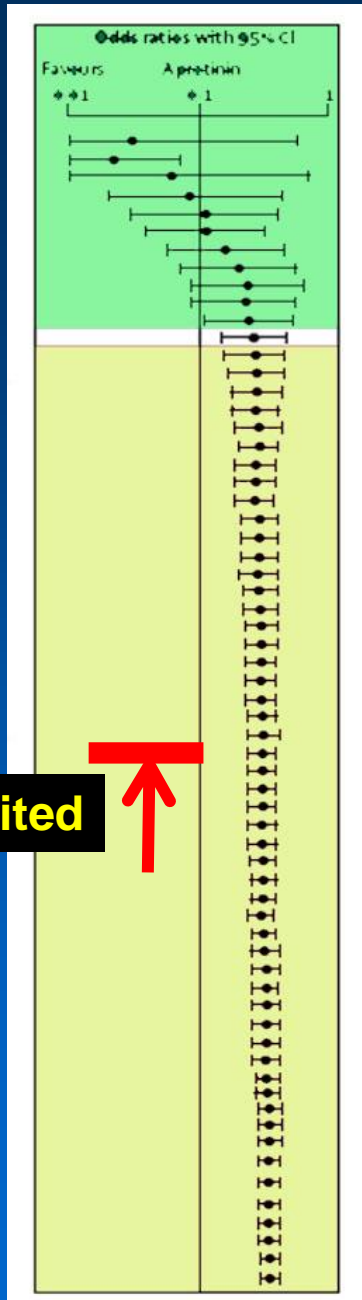
THEME SECTION: INFORMATION RETRIEVAL FOR HTA

**How much searching is enough?
Comprehensive versus optimal
retrieval for technology
assessments**

Andrew Booth

University of Sheffield

1987



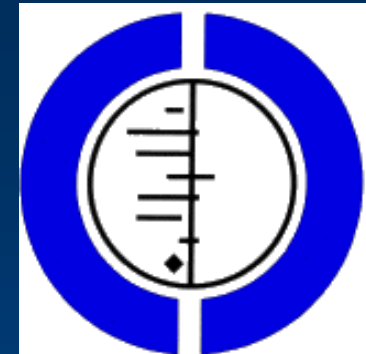
Cited

2002

RCTs of aprotinin in cardiac surgery to stop bleeding

Lancet 2005
Clinical Trials 2005

Current record count for the Cochrane Library



Database	Total Records
<i>Cochrane Database of Systematic Reviews</i> A breakdown of CDSR content is available here	9520
Cochrane Central Register of Controlled Trials	955,738
Cochrane Methodology Register	15,764
Database of Abstracts of Reviews of Effect	36,795
Health Technology Assessment Database	16,372
NHS Economic Evaluation Database	15,015
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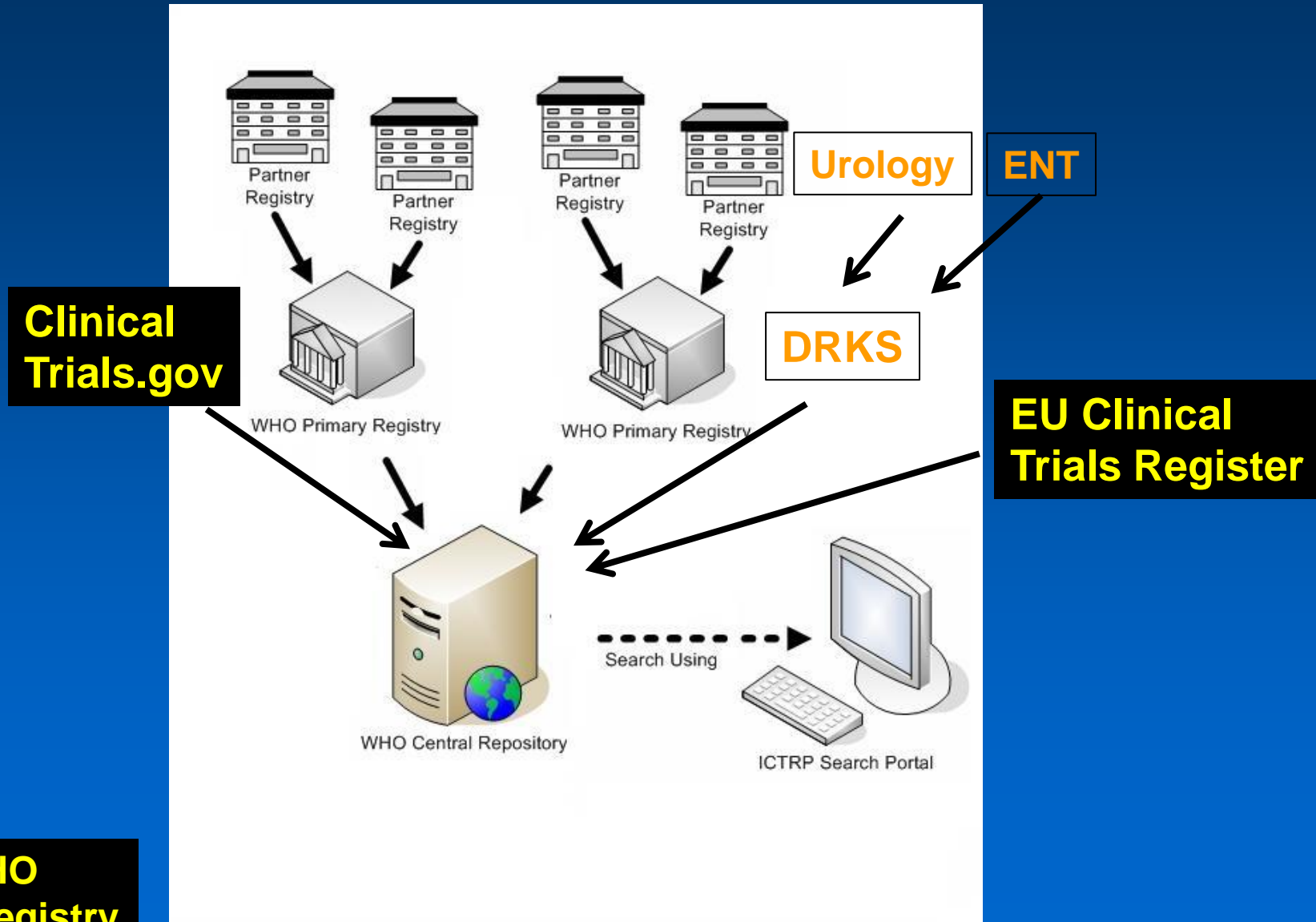


**Cochrane Library
Counts
September 2016**

**7004 reviews
2516 protocols**

**Impact Factor 2015:
6.103 (vorläufig)**

**Striving for quality:
Trial registration as a cost-effective tool**



Clinical Trials.gov

Urology

ENT

DRKS

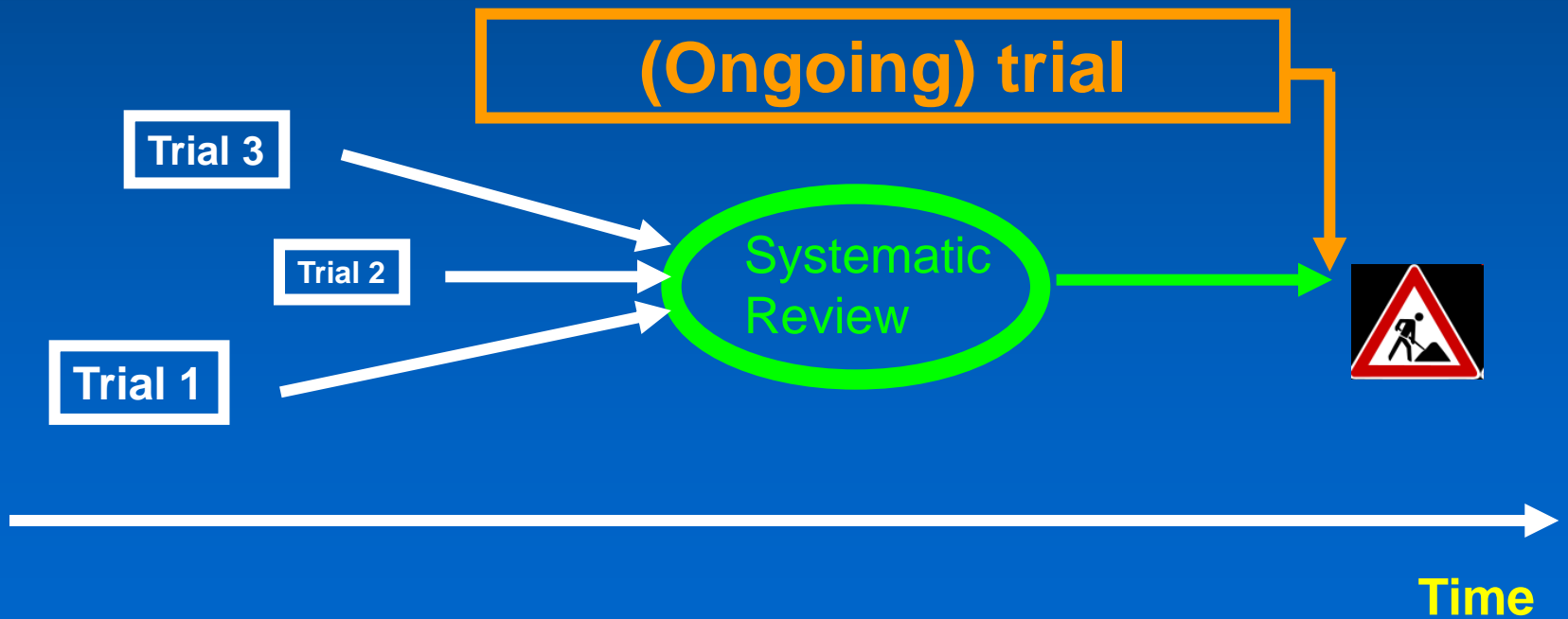
EU Clinical Trials Register

CT not WHO Primary Registry

Search Using

ICTRP Search Portal

Including ongoing trials into systematic reviews?



Is trial registration playing its role to achieve more publications

- Heterogenous registration rates, very low in some registries
- No sanctions, or, if sanctions, they are not applied
- Inconsistent conditions around the world

Next step to achieve more complete publication:

Results “registration“

(publication of primary outcome results in register)

Declaration of Helsinki 2013

"Research Registration and Publication and Dissemination of Results

*35. Every research study involving human subjects must be **registered** in a publicly accessible database before recruitment of the first subject.*

*36. Researchers, authors, sponsors, editors and publishers all have ethical obligations with regard to the **publication** and dissemination of the results of research. Researchers have a duty*

.



Systematic trial/study search today: Literature, study registries and beyond

- Traditional: Medline, Cochrane Library etc.
Restricted to completed studies



- Nowadays:
Search in registries for planned or ongoing studies



Increasing awareness of the relevance for (early) benefit assessment, pricing especially for new drugs, and for regulatory processes

- Beyond:
Access to study data; trial reports from regulatory authorities;
full data from trialists for individual patient data (IPD) analysis

Announcement: Where are the data?

07 September 2016



PDF



Rights & Permissions

As the research community embraces data sharing, academic journals can do their bit to help. Starting this month, all research papers accepted for publication in *Nature* and an initial 12 other Nature titles will be required to include information on whether and how others can access the underlying data.

These statements will report the availability of the 'minimal data set' necessary to interpret, replicate and build on the findings reported in the paper. Where applicable, they will include details about publicly archived data sets that have been analysed or generated during the study. Where restrictions on access are in place — for example, in the case of privacy limitations or third-party control — authors will be expected to make this clear.

The new policy (full details of which are available at go.nature.com/2bf4vqjn) builds on our long-standing support for data availability as a condition of publication. It also extends our support for data citation, the practice of citing data sets in reference lists in a similar way to citing papers. Authors are encouraged to cite data sets that have digital object identifiers (DOIs) assigned to them.

The introduction of data-availability statements follows a trial at five Nature journals — *Nature Cell Biology*, *Nature Communications*, *Nature Geoscience*, *Nature Neuroscience* and *Nature Physics* — that began in March 2016. The pilot confirmed differences in the culture of data sharing and access between different disciplines, and that the lack of obvious, public, community repositories

Related stories

- [The ups and downs of data sharing in science](#)
- [Data sharing: Access all areas](#)
- [Data-access practices strengthened](#)

Installed
early 2017

Bundesgesundheitsbl 2013
DOI 10.1007/s00103-013-1818-y
© Springer-Verlag Berlin Heidelberg 2013

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Biometrie und Medizinische Informatik, Universitätsklinikum Freiburg

Methoden des Evidence Mappings

Eine systematische Übersichtsarbeit

Aufgrund der kontinuierlich steigenden Zahl an wissenschaftlichen Publikationen ist es mittlerweile erforderlich, die vorhandene Evidenz zu einem Themengebiet systematisch aufzubereiten, um ein vollständiges und somit ausgewogenes Verständnis der Forschungslandschaft.

häufig einen edukativen Charakter. Die Auswahl der berücksichtigten Literatur erfolgt jedoch subjektiv und unsystematisch, was zur Verzerrung bei den Schlussfolgerungen führen kann.

Systematische Übersichtsarbeiten. Sys-

und somit der Leseaufwand für eine systematische Übersichtsarbeit für den Nutzer eine zusätzliche Herausforderung dar. Entscheidungsträger und Interessenvertreter im Gesundheitssystem plädieren deshalb häufig für substanzielle Evidenzaufbereitungen, die Forschungsergebnisse für



Research in context

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Volume 384, No. 9961, p2176–2177, 20 December 2014

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Comment

Further emphasis on research in context

Sabine Kleinert, Laura Benham, David Collingridge, William Summe

Panel: Research in context

Evidence before this study

This section should include a description of all the evidence that the authors considered before undertaking this study. Authors should state: the sources (databases, journal or book reference lists, etc) searched; the criteria used to include or exclude studies (including the exact start and end dates of the search), which should not be limited to English language publications; the search terms used; the quality (risk of bias) of that evidence; and the pooled estimate derived from meta-analysis of the evidence, if appropriate.

Added value of this study

Authors should describe here how their findings add value to the existing evidence (including an updated meta-analysis, if appropriate).

Implications of all the available evidence

Authors should state the implications for practice or policy and future research of their study combined with existing evidence.

findings? How can we improve the accessibility and usability of research findings, and data availability? And, finally, how can we further raise awareness and continue discussions on the topic of research productivity?

As a first step, we are strengthening our requirement to put research into context. Knowing and rigorously assessing the context and value of research will help editors make decisions about whether to publish a paper, and will help readers to interpret the importance of published research in addressing unanswered questions and building an evidence base. From Jan 1, 2015, all research papers, apart from systematic reviews and meta-analyses, submitted to any journal in *The Lancet* family must include a Research in context panel with an enhanced structure and subheadings (panel). Editors will use this information at the first assessment stage and

Comment

A new network to promote evidence-based research

Iain Chalmers , Magne Nylenna

Altmetric

DOI: [http://dx.doi.org/10.1016/S0140-6736\(14\)62252-2](http://dx.doi.org/10.1016/S0140-6736(14)62252-2)

 [Article Info](#)

[Summary](#) [Full Text](#) [Tables and Figures](#) [References](#)

To embark on research without reviewing systematically evidence of what is already known, particularly when the research involves people or animals, is unethical, unscientific, and wasteful.^{1,2}

More than two decades have passed since Antman and colleagues³ showed that research on some treatments for myocardial infarction had gone on for as long as a decade after benefit or harm had been established in earlier research. Failure to analyse epidemiological research cumulatively has also had devastating effects.

Among research regulators, the guidance for researchers issued by the Health Research Authority in the UK now states “Any project should build on a review of current knowledge. Replication to check the validity of previous research is justified, but unnecessary duplication is unethical.”⁹

Research on research has exposed a general failure to refer to existing evidence when reporting additional primary research.⁷ Other research has shown that this

A further obstacle: The language

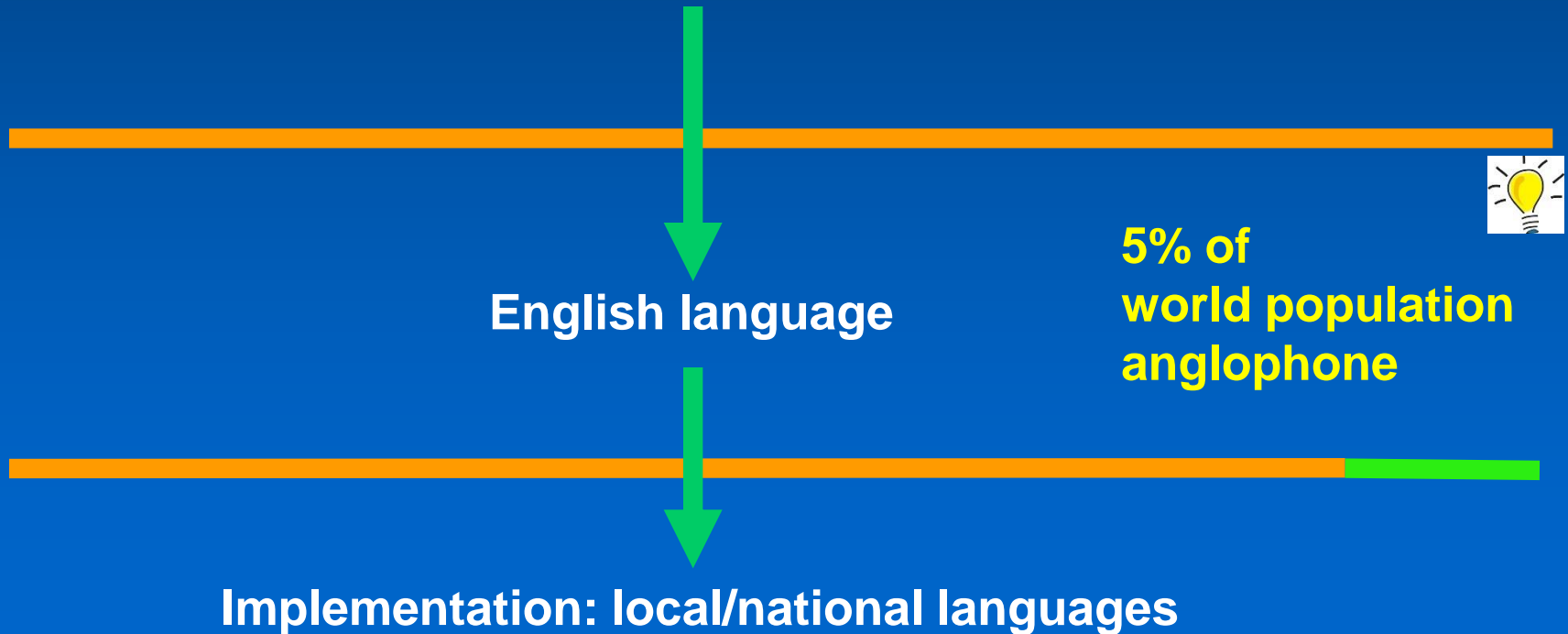
Transfer of Research into Practice

Answers to medical questions

- Clinical (randomised / controlled) studies
- Epidemiological (observational -) studies

.....

Knowledge Translation



**The new competitor:
Big data, innovation, personalized medicine . . .**

“Definition” of Big Data

3 V's

- Velocity
- Volume
- Variety

Analyze data from social media and networks, fotos, videos, MP3-data, blogs, search engines, tweets, emails, internet-telephony, music streaming, sensors of “intelligent devices“

4th production factor



Fundamental contradictions

- Big Data claims to analyze unstructured data
- Can only work if unlimited access to all data: ownership moves from private person to user
- Big data cannot reproduce results because everything is changing every second: real-time results
- The era of causality is over, now era of correlation (enabled by unlimited access to data)

A new Science(ability)?

(November 2nd, 2015) Big Data, Innovation, Personalised Medicine and co. – Are these the hallmarks of a new science(ability) in medicine? An essay by Gerd Antes, Freiburg.



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If one is to believe what one reads in editorials, comments or opinion articles in scientific journals then we are at the beginning of a golden age for patients and healthy people. Patients will be diagnosed much earlier and more correctly, and then treated accurately, efficiently and free of side effects by personalised medicine. Healthy people aren't at all at risk because they will be protected from becoming sick in the first place by perfect preventative healthcare.

THEMEN

Golden future or empty promises?

BIG DATA UND PERSONALISIERTE MEDIZIN

Goldene Zukunft oder leere Versprechungen?

Es erscheint überfällig, die Versprechungen für die Zukunft auf den Prüfstand der Qualitätsdiskussion (Good Scientific Practice) zu stellen.

Die Medizin scheint auf dem Marsch in eine goldene Zukunft zu sein. Die Forschung liefert eine stetig schneller wachsende Menge immer hochwertigerer Ergebnisse. Diese müssen nur noch in die Gesundheitsversorgung umgesetzt werden, was durch Translation der Forschungsergebnisse in die Praxis ein Leichtes sei. Alles, was man für den Sprung in die Zukunft braucht, sind der uneingeschränkte Zugang zu allen Daten und eine unbegrenzte Rechnerkapazität, um aus den ungeheuren Datenmengen in Echtzeit die geeigneten Regeln

Durchführung und Publikation von Studien wie auch die systematische Zusammenfassung von Wissen und dessen Implementierung.

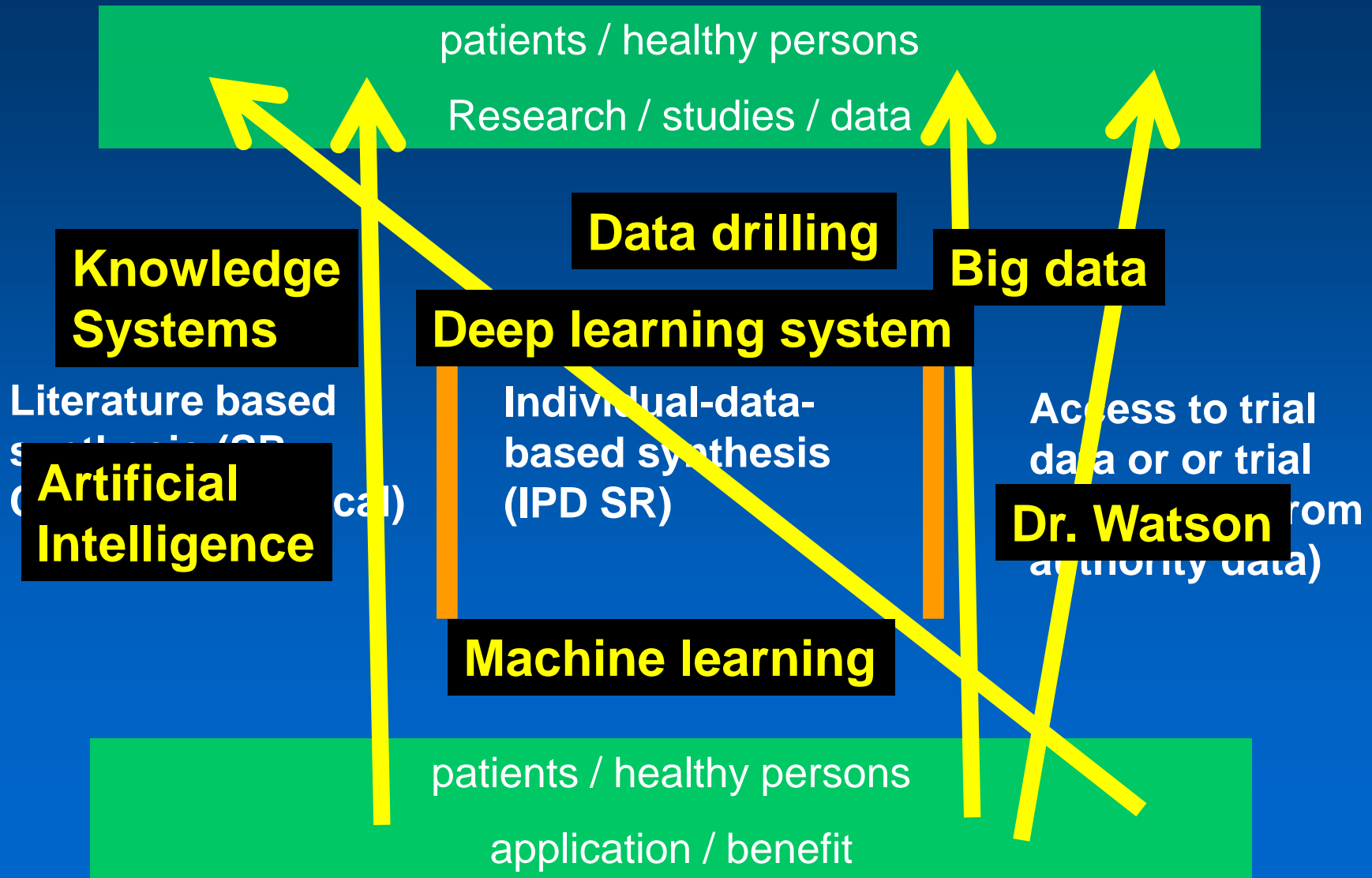
An zentraler Stelle ist die weltweit wie eine Naturkonstante herrschende Publikationsrate von 50 Prozent zu nennen. Das heißt, 50 Prozent der durchgeführten Forschung verschwindet und wird der Welt nicht präsentiert, was dem wissenschaftlichen Grundprinzip der Wissenskommunikation fundamental entgegensteht. Erstaunlich dabei ist, dass diese enorme Lücke seit Jahren beharrlich ist, jedoch weit

und Organisationen, so zum Beispiel von Nature und Science (2), zum Thema Nichtreproduzierbarkeit wissenschaftlicher Experimente. Hintergrund ist die seit Jahren zunehmende Erkenntnis über die mangelhafte Reproduzierbarkeit und Verifizierbarkeit eines Großteils der Ergebnisse aus dem Wissenschaftsprozess, die in der Folge zu Irrwegen, Fehlentwicklungen und -investitionen führt. Dass dies aus ethisch-moralischer Perspektive wegen der unmittelbar folgenden Schädigung von Menschen nicht zu verantworten ist, liegt auf der Hand.

Good scientific practice?

- No theory
- No validation and/or evaluation, only anecdotal evidence
- Abolishing basic rules of good-scientific practice
- No notion of quality?
- Clash of cultures with the old world of EBM, Cochrane etc.
- Is Big Data making the information specialist obsolete?

Transfer of research results into practice



**The new enemy?
Open access, data sharing . . .**

More knowledge from more (*predatory scholarly open-access*) journals?

- Thousands of new journals with Open-Access
- Financing shifted from readers to authors
- Enormous market expansion can only be covered by lower quality

The political context

Broad reluctance and resistance against . . .

- . . . transparency
- . . . genuinely sharing data and results
- . . . researcher- and business-driven agenda, dominated by competition

What to expect from information specialists

The ideal information specialist . . .

- . . . plays a crucial role in summarizing the existing knowledge, understanding the global knowledge structure and uses SR methodology to support research and health care with reliable information
- . . . is involved in the planning of projects in an early stage
- . . . plays an active role in teaching and training researchers and healthcare providers
- . . . supports the production, updating and dissemination of local language information (abstracts and lay language summaries)

Summary

- . . . is supporting activities to achieve better recognition of knowledge as key factor for better health
- . . . is involved in setting up a knowledge culture and integrating global knowledge and local implementation
- . . . helps to increase value and reduce waste of medical research and thus helps to improve health care